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DOI:

[10.1093/ageing/afq054](https://doi.org/10.1093/ageing/afq054)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Lawrence, V., & Murray, J. (2010). Balancing independence and safety: the challenge of supporting older people with dementia and sight loss. *Age and Ageing*, 39(4), 476 - 480. [afq054]. <https://doi.org/10.1093/ageing/afq054>

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Balancing independence and safety: the challenge of supporting older people with dementia and sight loss

Background: Dementia and visual impairment are common in older adults and both conditions create a high risk of disability. Care professionals lack evidence on how best to support older adults with both conditions.

Aim: The study investigated attitudes towards working with older adults with concurrent sight loss and dementia, the challenges involved, and suggestions for service development.

Methods: A qualitative study comprising 18 in-depth interviews and 2 focus groups with care professionals within mental health and low vision services.

Results: Care professionals were alert to the high levels of risk among patients with joint sight loss and dementia. In-depth interviews revealed that insufficient time and expertise can lead to an over cautious approach that prioritises the reduction of risk, rather than promotion of independence. Focus groups highlighted the role that joint working can play in supporting older adults' valued roles and activities. Barriers to joint working were identified alongside strategies to assist the process.

Conclusions: It is essential that care professionals and service providers acknowledge and respond to the complex needs of this population. Joint working was considered key to assessing risks and targeting interventions. The research workshop presented here provides a useful format for improving practice across inter-professional boundaries.

Introduction

Dementia and visual impairment are common in older adults with the prevalence of both conditions increasing rapidly with age. More than 12% of those over the age of 75 are visually impaired [1] and 5% of people over 65 have a form of dementia [2]. Moreover, evidence suggests an association between visual impairment and the risk of cognitive decline [3] and Alzheimer's disease [4, 5] in older people. This co-morbidity can be expected to rise as the UK population ages, yet few studies have examined how sight loss and dementia affect the lives of older adults or the family members and care professionals who support them.

The implications of concurrent sight loss and dementia are likely to be considerable: dementia is one of the major causes of disability in older adults [6] and visual impairment, and the perceived loss of independence attached to the condition, has been reported to evoke more fear in older adults than any other physical impairment [7]. Whitson (2007) confirmed that individuals with coexisting cognitive and visual impairment are at high risk of disability, with the combined impact greater than for either condition alone [8]. This acknowledged the high level of need in this population, but did not elaborate on the mechanisms through which disability was formed. Woods (1999) notes that the institutional or caregiving context can reinforce dependency in people with dementia and create more disability than the neurological impairment would dictate [9]. There is evidence that managing risks can constrict personal autonomy in people with dementia [10]. Visual impairment may further increase vulnerability to risk, which in turn, may perpetuate a more protective approach. Low vision services and mental health services aim to promote independence, autonomy and choice, but lack evidence on which to base their approach for this group of older people. This paper presents a qualitative study with two phases: the first investigated what it is like to work with older adults with acquired

visual impairment and dementia and the second examined how services and support might be improved to meet the needs of this population. The research was funded by the Thomas Pocklington Trust.

Method

Part 1 used a case study approach comprising in-depth interviews with older people with serious visual impairment and dementia, family carers and care professionals. This paper will focus on the attitudes and experiences of the 18 care professionals that took part in the research, who were recruited from mental health and low vision services (consequently we present the participant characteristics of the care professionals only in Table 1). The sampling strategy and data from the interviews with the older people and family carers are described in detail elsewhere [11].

Interviews with care professionals explored the perceived impact of dementia and sight loss on patients, attitudes towards working with individuals with both conditions, the challenges involved, and how it affects their professional role. Recruitment continued until theoretical saturation was reached, that is until no new themes were emerging from the interviews. Interviews lasted around 1 hour, were tape-recorded and transcribed verbatim. Constant comparison analysis was used to identify underlying uniformities and diversities in the data through which categories were formed [12]. Table 1 shows the care setting and job titles of the care professionals in Part 1 and 2.

Many of the recommendations from Part 1 had implications for the roles of professionals. In response, a research workshop was conducted to initiate a dialogue between key professionals working with older adults with dementia and / or sight loss within the same locality. Seventeen professionals attended, including low vision rehabilitation workers, community psychiatric nurses, occupational therapists, clinical psychologist, social workers, day-centre and residential care managers.

Balancing independence and safety

Participants were recruited on the basis of expertise and interest in the area. The workshop commenced with a brief presentation of the findings of the case studies conducted in Part 1. This was followed by two parallel focus groups (each lasting 60 minutes and consisting of 8 and 9 people respectively) that explored key areas of concern and suggestions for service developments. The use of a vignette depicting an older adult with dementia and serious visual impairment facilitated a concrete discussion of the identification and management of needs. Each focus group comprised participants from different professional backgrounds, which provided an opportunity to identify divergent and shared perspectives [13]. Following the focus groups participants reconvened to discuss the implications of the workshop. The sessions were tape recorded, transcribed and subjected to constant comparison analysis.

Results

Part 1 (In-depth interviews)

Prioritising safety

Care professionals felt that the risks associated with being partially sighted or blind were amplified by the co-existence of poor memory, and to an even greater extent, by diminished capacity to deal with risks rationally. Although both sight loss and mental health professionals stated that their role was to promote clients' independence and safety, they were mindful of the inherent conflict in these aims. Low vision rehabilitation workers explained that routine activities such as retraining individuals to use the cooker, make a cup of tea or walk to the local shops became fraught with difficulties when working with older adults with memory problems. Some

Balancing independence and safety

feared that this led them to adopt an overcautious approach and many felt deskilled in these circumstances.

“Quite often I feel overwhelmed and out of my depth really that I could probably do more and I don’t know who to turn to. Maybe I should go and spend some time with the memory services...” (CP7, Rehabilitation Worker)

Others felt that their difficulties stemmed from the false expectation that sight loss could be dealt with in isolation. Rehabilitation workers criticised their training for failing to equip them with the expertise to work with clients with concurrent mental health problems, and criticised GPs and mental health teams for failing to provide them with adequate information regarding additional complaints. Mental health staff expressed fewer reservations about working with older adults with both conditions and generally believed that referrers would relay this information if significant. Staff based in community mental health teams, memory clinics, and care homes identified themselves as working holistically to meet multiple needs. However, visual impairment often appeared to assume a low position on the list of priorities and few felt that it would have a significant effect on the way that they worked with their clients.

“It’s just something that goes with the territory really...I mean yes you tend to use sort of touch more to make sure that they know that you are there but otherwise not really, it doesn’t make that much of a difference”. (CP10, Community Psychiatric Nurse)

Staff within care homes reflected that they sometimes lacked the resources to provide the necessary support to older adults with concurrent sight loss and

Balancing independence and safety

dementia e.g. constraints on time and staffing meant that some clients were fed rather than being encouraged to eat independently. There was little evidence of joint working between mental health and sight loss professionals. However, it was felt that increased contact between the teams would provide a more holistic understanding of the individual and their capabilities and how support could be targeted to maximise their independence. The manager of the day centre for people with sight loss and dementia endorsed this approach.

“We receive referrals from the sensory impairment team and in doing so we would then liaise with them to find the best working method and the best working plan for any individual as well as other departments, old peoples’ mental health teams, occupational therapy teams, physiotherapy”. (CP18, Director, voluntary organization for people with sight loss)

Part 2 (Workshop)

Prioritising independence

The prevailing response to both the presentation of research findings and the vignette was the imperative of prioritising the individual. There was consensus across the professional groups that individual preferences must form the cornerstone of any approach. Capacity, rather than incapacity, should be assumed, and care professionals should avoid making assumptions about individuals’ needs, abilities or wishes. Professionals acknowledged the importance of supporting older adults in maintaining valued activities. A common view was that risks should be carefully assessed through discussions with the family, multidisciplinary team, and the individual themselves. One clinical psychologist identified the need to “balance

Balancing independence and safety

quality of life and accepted risk". In this context, the challenge was to adequately assess, discuss and document risk.

"You mustn't take their independence away. We've a lady who would slip out and go for walks. Well we can't stop her, we don't want to stop her, we just make sure she is all wrapped up with gloves and a scarf and then a member of staff will follow her, not so it's obvious, but just sort of discreetly monitor her....but this all has to be discussed with the family and documented".

(Deputy Manager, voluntary organisation for people with sight loss)

This was accompanied by awareness that situations change and should be reassessed regularly.

Importance of joint working

Each professional group identified maintaining the individual's valued elements of life as their primary goal and joint working as instrumental to achieving this. They stressed that professionals should not assume the individual's sight or cognition to be intact, and should instigate referrals for more specialist assessment where there was doubt. There was strong support for conducting joint assessments, as it was felt that this would help to establish the root cause of the client's difficulties and facilitate the most appropriate response. This would instil greater confidence in the assessment of client's functioning, as professionals would not have to rely solely on their knowledge of a condition that was outside their specialism. The vignette provoked discussion of the many opportunities for joint working, and participants became increasingly optimistic about what this would enable them to achieve. There was a strong sense that utilising colleagues' expertise would contribute to a more imaginative way of working.

“I think actually there is enormous learning in joint working as well you know when somebody says well I would be looking at this in this way, and then I could say well I would look at it this way, and this can dovetail together.”

(Rehabilitation worker)

Challenges to joint working

Despite the enthusiasm for joint working, participants confirmed that assessments of mental health and vision were typically undertaken in isolation. Mental health professionals stated that they lacked a clear understanding of the role of sensory impairment teams. Uncertainty also existed among mental health and sight loss professionals regarding the practicalities of accessing the respective teams. Participants explored this confusion and offered clarification. For example, rehabilitation workers assured mental health professionals that they would respond to enquiries even if a client were not registered with their team. Informal contact of this sort was considered useful.

“I suppose it’s like willingness on both parts. There is a lady who is an expert on assistive technology and you can phone her up and she will be happy to come out and talk things through with you. It sort of encourages you I suppose to try to do joint assessments. So you know maybe it’s about being aware of rehab and maybe starting to make contacts.” (Occupational Therapist)

Improving joint working

Balancing independence and safety

Formal mechanisms were also proposed to assist the process of joint working.

Participants discussed the benefits of a consultancy service in which a member of the low vision team would specialise in dementia and liaise between the teams.

Another suggestion was that mental health professionals could shadow rehabilitation workers, and vice versa. Rehabilitation workers re-emphasised the necessity of promoting their roles to other professionals. Participants unanimously supported the use of team presentations in raising awareness of services and training in transferring knowledge and skills.

“The psychiatric team are very good at coming in and if you ask them to do training they will. You know, how to orientate somebody who is blind and got dementia. We give them our information and they give us their information, it is an exchange, which is quite good” (Deputy Manager, voluntary organisation for people with sight loss)

Raising awareness of services was identified as a continual process, as teams constantly change and impetus can be lost. Some participants believed that routinely considering the impact of sensory impairments, rather than regarding this as a secondary issue, would require a cultural change in dementia services. Once again, however, there was concern that limited resources and pressures on staff might result in these needs being overlooked. Lastly, mental health and sight loss professionals reported that they had increased their knowledge of the respective services through attending the workshop and appreciated the opportunity to build contacts with members of other professionals groups.

Discussion

Balancing independence and safety

In-depth interviews highlighted the profound threat that concurrent sight loss and dementia posed to older adults' independence. Care professionals were alert to the heightened level of risk among this population and reflected that insufficient expertise and / or resources may engender an over-cautious approach. This may impose excess disability on the older person [9]. The focus groups that followed prioritised the individual, arguing that services must support people with dementia and sight loss in maintaining valued roles and activities. Emphasis was placed on personhood and preserving older adults' integrity and value, rather than simply promoting independence in task performance, which may not always be achievable [14] and cannot be assumed to lead to higher levels of well-being [9]. Yet there was consensus that this required older adults, their relatives and care professionals with different expertise to reach a shared understanding of the risks and how these can be managed [15].

Guidelines for dementia services [16] and low vision services [17] highlight the necessity of a co-ordinated multi-agency approach in service delivery, yet evidence suggests that this is not always achieved [18]. The present data helps to identify specific barriers to joint working, such as a limited understanding of other professional roles, and strategies to assist the process. The National Dementia Strategy [19], promulgates the importance of leadership for dementia through the nomination of an individual staff member in care homes and general hospitals. Participants in this study suggested a lead role for dementia in sensory impairment teams. Team presentations, joint training and "shadowing" were also suggested. Finally, participants agreed that the research workshop itself promised to improve practice across inter-professional boundaries and that this format could successfully be replicated elsewhere.

A potential limitation of this study is that participants may have a particular interest in the area that is unrepresentative of staff as a whole. However, it is the extent to which the attitudes of these participants changed over the course of the research that is perhaps most striking. This demonstrates the potential of using qualitative methods in action research to identify problems in clinical practice and develop potential solutions [20]. It is essential to remain mindful of the challenges identified in the interviews such as the practical constraints that exist within the workplace. Research workshops can raise the profile of neglected areas of health and social care need, such as the implications of sight loss in mental health settings, but service providers must also acknowledge that assessing and responding to the complex needs of older adults with concurrent sight loss and dementia requires extra resources.

Key points

1. Care professionals lack evidence on how best to support older adults with concurrent dementia and sight loss.
2. This can lead to an over cautious approach that prioritises the reduction of risk, rather than promotion of independence.
3. Joint working is vital in supporting people with dementia and sight loss in maintaining valued roles and activities.
4. Mental health and sight loss teams should explore possibilities for developing joint working e.g. “dementia lead”.
5. The research workshop described in this paper promised to improve practice across inter-professional boundaries.

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Table 1. Care setting and job title of care professionals

| Type of service | Job title | Number of people in Study 1 | Number of people in Study 2 |
|---|----------------------------------|-----------------------------|-----------------------------|
| Low-vision Rehabilitation | Team Manager | 2 | 2 |
| Team | Senior Rehabilitation Worker | 2 | 2 |
| | Rehabilitation Worker | 2 | 0 |
| Voluntary organisation for people with low-vision | Director | 1 | 0 |
| | Group Leader | 1 | 0 |
| | Service Coordinator | 1 | 0 |
| | Counsellor | 0 | 1 |
| | Support Worker | 0 | 1 |
| Residential care for older people with sight loss | Deputy Manager | 1 | 1 |
| | Activities Coordinator | 1 | 0 |
| Voluntary organisation for people with sight loss | Support Worker | 1 | 0 |
| | Resources Worker | 0 | 1 |
| Nursing Home for the Elderly | Deputy Manager | 1 | 0 |
| Mentally Infirm | Nurse | 1 | 0 |
| Community Mental Health | Community Psychiatric Nurse | 2 | 1 |
| Team for Older Adults | Senior Occupational Therapist | 1 | 0 |
| | Occupational Therapist | 0 | 4 |
| Memory Clinic | Consultant Clinical Psychologist | 1 | 1 |
| Social Care Mental Health | Head of Social Care | 0 | 1 |
| Older Adults Directorate | | | |
| Older Adults Social Care | Social Worker | 0 | 2 |
| | TOTAL | 18 | 17 |